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ABSTRACT

This guidebook is intended to assist parents of children with disabilities who will be returning to the state of Maryland because of Senate Bill 588, which strongly discourages out-of-state placements of individuals with disabilities or other special needs. The first section is on "getting ready" and provides a summary of Senate Bill 588, an interpretation focusing on the timeline for returning children to in-state care, answers to commonly asked parental questions, and a form for logging relevant information during the process. The second section discusses setting up the child's program. It includes information on the individualized education program (IEP) or individualized service plan, a student profile, considerations for the IEP, the concept of "wrap around care," forms for tracking contacts, and a sample letter for obtaining names and telephone numbers of support personnel. The final section focuses on keeping the child's program going. It provides information and suggestions on successful transition, managing change, key contacts, and a conference log form. Also included are a glossary of terms associated with Senate Bill 588 and a list of agency abbreviations. (DB)

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PROJECT RETURN:

A Parent's Guidebook

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Also:

Pitts, R. J., Jr., and Marchitell, C. K.:

Rays of Hope: The Special Child and the Family [1994]

Pitts, R. J., Jr.:

Success Factors in Group Home Programs for the Severely and Profoundly Retarded [1992]

Marchitell, C. K.:

Effect of Institutional Change on Perception of Control [1993]

"Learning to Lead" [1991]

"Evaluating the Performance of the Performance Evaluation" [1987]

"To Be or Not To Be Hunterized" [1986]
with Alice A. Campbell, M. A.

"Culture, Commitment, and the Computer" [1984]

Misunderstood Monster: Research Paper in the Classroom [1982]

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Welcome to Project Return

This guidebook is for parents of children who will be returning to the state of Maryland because of Senate Legislation 588.

As parents of children who have already returned, we sometimes feel overwhelmed by managing all the aspects of the project. Yet, as the only permanent administrators of our chidren's care and education, we must be certain that the wraparound aspects of Senate Legislation 588 really *do* wrap around our children and meet their needs.

There is no set pattern for smoothing the 90 - day transition period from out-of-state care back to Maryland. The uniqueness and priorities of each child make such a pattern an impossibility. However, we can tell you the steps and approaches we found useful during our journey through Senate Legislation 588. We think you can avoid many delays and frustrations. We hope this guidebook will help you put together a comprehensive program and assure a successful transition.

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SECTION 19.1.-- Applies specifically to the placement of children with special needs and declares that it is the policy of the State of Maryland to provide for and encourage the development of a continuum of quality education, treatment and residential services for the children of the state to the extent that funds are available. This includes serving children in their homes or in the least restrictive setting appropriate to their individual needs unless the State has determined that the individual needs of the special needs child cannot be met through additional support of the nonresidential school, home, foster home, alternative living unit or group home. The State may not fund the placement of a child in a more restrictive setting and it must prevent the unnecessary out-of-state placement of children with special needs.

PARENT PARTICIPATION IN WRAP AROUND CARE:

MANAGING A VARIETY OF SERVICES, AGENCIES, AND PROGRAMS

SECTION ONE:

GETTING READY

SENATE BILL 588:

What follows is an executive summary of Maryland's project to return individuals with disabilities and other special needs, as well as to avoid future out-of-state placements.

Senate Bill 588 addresses:

- how local and state planning entities will develop the range and quality of services needed;
- required changes in licenses and rate setting;
- flexible funding strategies and resources for the development of a broad range of services;
- the amount and sources of funds necessary to accomplish the whole project.

There are several elements and divisions within the project. One includes the definition of special needs children affected by Senate Bill 588 as those who are:

- currently in out-of-state placement funded by the local or state agency;
- referred to the Local Coordinating Council (or the State Coordinating Council) for imminent out-of-state placement.

Also included in the project are:

- a description of Maryland's comprehensive service system continuum;
- identification of existing facilities and service gaps;
- recommendations for resource development and fiscal strategies;
- local implememtation strategies and training needs;
- detailed schedules of implementation and timelines for return of children from out-of-state placement;
- the appointment of an oversight committee for implementation.

Questions and Notes:

WHAT DOES ALL OF THIS MEAN?

The State of Maryland must set up a system to meet the care requirements of our special needs children without altering the quality of their individual programs. In short, despite the change in location and personnel, there will be no change in the quality of care--a fact that comforts us all.

The timeline for returning the chidren to in-state care depends on several factors. The primary one is the total number of children with special needs living within the jurisdiction of the particular school system.
Each system must:

- establish its own Local Planning Entity (LPE);
- develop an individualized service plan for each family;
- locate appropriate resources;
- submit the jurisdiction's plan to the state for approval and disbursement of funds.

Local Planning Entities are responsible for development of interagency service plans, goal setting, and allocation of resources.

Not all school systems have established start-up dates, and some systems do not have Local Planning Entities yet. Within several months after the trigger date, systems must move the children. To find out the trigger and implementation dates for your jurisdiction, call your local Board of Education.

Current provisions for return to Maryland communities from out-of-state facilities create many questions that naturally accompany any change.

You will probably want to know:

1. What risks are part of the transition?

Information that is too little, too complex, or too late can make parents and service providers feel confused, discouraged, or uninvolved.

2. Where is the money going to come from?

Services and activities can be funded by federal, state, and county programs and institutions; public agencies; private organizations; and concerned individual families. In returning to Maryland, children should not lose the financial support necessary to meet their needs.

3. Who is responsible for what?

Federal law says that all children -- including those with disabilities -- are entitled to free and appropriate public education. In Maryland, local schools supervise and coordinate the accommodations necessary chilgren with special needs. Each agency and service has its own operating guidelines, evaluation procedures, and personnel. Parents are the people in the system who are most likely to represent the consistency necessary to monitor the overall welfare of their special children.

4. How do parents communicate with the system?

Parents learn whom to contact about which matters. They ask questions. They voice concerns. They get answers. They stay up-to-date. And they keep good records.

5. How do parents get trust and respect from the system?

Parents earn credibility through documentation. They keep track of contacts, decisions, events, and information about their children.

6. What benefit comes from Senate Bill 588 transition?

Children with special needs will be able to enjoy lives in their own homes, schools, and communities that are as full and rewarding as possible.

Information Log

(This information proves helpful in many ways and saves time in the long run.)

Names and phone numbers of your local Board of Education (BOE) contacts:

_____ _____

_____ _____

_____ _____

Trigger Date: _____ **Implementation Date:**_____

Names and phone numbers of the members of your Local Planning Entity (LPE):

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

Questions you have for the BOE or LPE:

SECTION TWO:

SETTING UP YOUR PROGRAM

The IEP: Key to Wrap Around Care

All students with disabilities are entitled by law to free, appropriate public education (FAPE).

Each county operates its own management system to oversee the enforcement and implementation of that federal mandate.

Some children need extra resources to meet that goal.

The Code of Maryland Regulations (COMAR) Programs for Students with Disabilities includes guidelines for special services to meet special needs.

Decisions about who receives services and what types of services must be based on individual needs and cannot be categorical.

The Admission, Review, and Dismissal (ARD) Committee of the local school supervises the program by which the school meets its educational obligation to children with special needs.

The ARD must consider whether a student needs Extended School Year services (ESY) in order to have a free, appropriate public education.

The program for each special needs child is called an Individualized Education Program (IEP).

The school and parents work together on the IEP which determines which special accommodations are necessary for the child's development of critical life skills, avoidance of regression in like skills, and support of reasonable recoupment in skills.

The IEP is reviewed, by all the people involved, at least once a year. When the IEP is started, and whenever a substantial change is recommended, an extra conference takes place after 60 days.

Moving into Maryland from out-of-state placement makes major changes in the IEP.

Since the IEP is individualized, clear understanding of its terms is essential for everybody involved. We recommend these ways to make sure you know all the conditions of your child's return:

- Find out who is working in your child's network of advisors and caregivers, and keep your information complete and up-to-date. *(Pages in this guidebook will help.)*
- Work consistently to stay in communication with the people who provide your child's wrap around care.
- Read the glossary of terms and the list of official abbreviations. *(They're right here in this guidebook to make reference easy for you.)*
- Write letters of understanding to appropriate people regarding: agreement abour payable funds; interpretation of services; clarification of procedures. *(There is a sample provided in this guidebook for you to modify if you want to use it.)*

STUDENT PROFILE
PART ONE
PERSONAL DATA

(We found that having a written reference for this information helped us manage the transition.)

NAME _____

DATE OF BIRTH _____ CURRENT AGE _____

HEIGHT _____ INTENSITY SPECIALNEEDS:_____
WEIGHT _____ LEVEL ___ _____

SCHOOL _____

DIAGNOSIS _____

CAUSE _____

CURRENT STATUS

(A brief summary of the current placement and the funding level for which the child is eligible.)

OUTLOOK

(Your assessment of how your child is progressing and what you expect.)

STUDENT PROFILE
PART TWO
FAMILY STRUCTURE

RESIDENTIAL LOCATION:

PARENTS:

SIBLING STRUCTURE:

NAME	AGE	SCHOOL	GRADE

CONSIDERATIONS
FOR THE
INDIVIDUALIZED EDUCATIONAL PROGRAM

The IEP or Service Plan combines many considerations and recommendations to customize an educational program for each of our special children. These are some general areas that we may have to make fit the specific needs of our children:

- STUDENT / TEACHER RATIO
- NUMBER OF CARE HOURS REQUIRED
- NUMBER OF WEEKLY HOURS OF PHYSICAL THERAPY SESSIONS
- NUMBER OF HOURS OF WEEKLY RESPITE CARE
- FREQUENCY OF CROSS TALKS AND COMMUNICATIONS SESSIONS

These considerations are generic, and their inclusion in the IEP is negotiable according to the intensity classification of the child.

Some children may require more of the allowable hours than others will.

These involved professionals should be represented in the IEP conference to guarantee the best results for our children:

- TEACHERS AND SUPPORT STAFF
- SOCIAL WORKERS
- RESPITE CARE WORKERS
- PHYSICAL THERAPISTS

Wrap Around Care

Federal legislation mandates the development and use of appropriate resources to serve students with disabilities. The goal is to provide the children with these resources within their own states or communities, within the least restrictive environments, with services that wrap around the children.

These services are:

- developed, approved, or both, by an interdiscipline service team
- community-based and unconditional
  (Unconditional means that the services cannot be denied because of severity of difficulty, and they must change as the needs of the student and family change.)
- based on strengths of the students and their families
- coordinated, highly individualized services in three or more life domains

The Local Coordinating Council identifies children with special needs.

The Local Regional Council guides the local school and affected families through Senate Bill 588 transition.

Special needs must be met in the environment which is least restrictive, closest to home and community, and appropriate for the student.

Parent credibility with the system comes from effective participation in implementation and from faithful documentation. Case files can get cumbersome, neglected, or lost. Even when they are complete, they are not easy to read or find information in.
When we keep good records for reference, history, and planning, we become a strong partner in the system. The more successfully we work with the Board of Education whike our children are in school, the more successfully we will work later with services for our children as adults.

Individualized Service Plan
Personnel for _____

(We found that keeping a list of all the professionals we deal with simplifies things for everyone.)

Name	Position	Work Phone

CONTACT PERSONNEL

(This has been a quick and handy tool for us.)

MEDICAL Contact: _____ Number: _____	**DENTAL** Contact: _____ Number: _____
RECREATION AND LEISURE Contact: _____ Number: _____	**SOCIAL SECURITY** Contact: _____ Number: _____
FAMILY RELATED SERVICES Contact: _____ Number: _____	**SCHOOL** Contact: _____ Number: _____
FOSTER CARE Contact: _____ Number: _____	**INSURANCE BENEFITS** Contact: _____ Number: _____
VOCATIONALREGIONAL Contact: _____ Number: _____	**ADMINISTRATOR DEP'T OF ED** Contact: _____ Number: _____
RESIDENTIAL PLACEMENT Contact: _____ Number: _____	Contact: _____ Number: _____
Contact: _____ Number: _____	Contact: _____ Number: _____

[date]

[name of contact or resource]
[job title or position]
[street address]
[city, state, zip code]

Dear [_____]:

On [date], [your child's name] will return to the State of Maryland under the guidelines of Senate Bill 588. The following is my understanding of the terms and conditions under which funding [and/or care and/or services] will be provided:

Funding and identified support service requirements will continue uninterrupted as stipulated in the current Individualized Education Plan, as though [he or she] had remained in out-of-state placement. Changes in the IEP [or Individualized Service Plan] will be reviewed with me by local school representatives.

[*INSERT ALL THE INFORMATION YOU HAVE TO DESCRIBE YOUR CHILD'S CURRENT CARE SITUATION AND SPECIAL NEEDS.*]

As my child reaches the age of twenty-one, [he or she] will no longer be eligible for these provisions under the supervision of Maryland Schools. In anticipation of that time, I will need assistance in arranging suitable care at the appropriate level of intensity.

[*INSERT ALL THE INFORMATION YOU HAVE TO DESCRIBE YOUR CHILD'S FUTURE CARE SITUATION AND SPECIAL NEEDS.*]

1. Please tell me the names and numbers of the administrative and support personnel who will be helping me coordinate my child's care during both care periods.

2. If this letter reveals any misunderstandings on my part about the procedures and services for my child, please notify me immediately.

3. If there are any adjustments in the guidelines under which my child will return to Maryland, please contact me personally at [phone number].

Sincerely,

[your name]

[add your address]

SECTION THREE:

KEEPING YOUR PROGRAM GOING

Successful Transition

During transition, we parents need to remember that our participation is critical. We will be working in partnership with administrative agents, support personnel, primary facilitators, agency representatives, and caregivers. Administration, services, and funding are available now, but procedures for family involvement and inter-agency communication may not yet be complete.

Once we have put together a comprehensive program to meet the needs of our special children, we will want to stay active. No matter how good the community based living plan is, it will not always run smoothly, and changes will happen. By our awareness and flexibility, we can use those changes in ways that are most helpful to our children's situations. We will also use those changes in planning for future benefits.

By the time they reach 21, children with special needs move out of BOE responsibility. This time will bring another period of transition: perhaps new administration, new personnel, new services, and new policies. But that time, we will be even better prepared to handle the changes. Clear understanding of the components of community based living, awareness of existing services, informed involvement, and careful planning for the future will bring another successful transition for our children--this time into adult living in our Maryland communities.

Managing Change

Throughout our children's lifetimes, changes will continue to happen. Our mission is to respond responsibly to changes in our children's development and situation. We can steer between more restriction than is necessary and less supervision than is safe. We will stay alert.

Here are our suggestions for managing changes.

Keep consistent, accurate documents to help in managing your child's wrap around program.

- Keep logs and notes about your contacts with the system.
- Keep records up-to-date.
- Bring records to meetings and review conferences.
- Have records ready to refer to during phone calls.

A change in administration can bring a change in policy.

- Ask questions. Get answers.
- Find out how new policies may affect your child's current program.
- Think through how a policy change might affect your child's program in the future.
- Try to anticipate policy changes when you plan.
- Head off problems before they occur.

Your informed participation will benefit everyone involved.

A change in personnel can bring a change in quality of care.

- Ask questions. Get answers.
- Become familiar with the qualifications and attitudes of the people who participate in your child's program.
- Voice your concerns to your contact people, representatives, and liaisons.
- Attend all IEP and planning conferences.

You are the only full time monitor and advocate. Your consistency will benefit your child.

Key Contacts

You may need information from other people, too. People in the following positions can help you get in touch with the resources in your area.

Systems Reform Initiative Parent Coordinator .....

Senior Resource Specialist / Return from out-of-State
Systems Reform Initiative [OCYF] .....

Chief, Nonpublic Schools Branch [DSE, MSDE] .....

Child Placement Coordinator [OCYF] .....

Executive Director, Baltimore City
Family Preservation Initiative .....

Department of Human Resources Representative to SCC
[responsible for coordinating #588] .....

Branch Chief
Program Administration and Support .....

Other area listings:

[Name and Position/Title] [Address and Telephone]

CONFERENCE LOG

(You may want to make additional copies of this to aid in your long-term record keeping.)

Conference notes at _____
name of school

regarding _____
your child's name

DATE	PROBLEMS NOTED	CHANGES MADE

Glossary of Terms Associated with Senate Bill 588

ARD

Admission, Review, and Dismissal Committee.
Each local public jurisdiction must maintain an ARD committee which serves with the authority of the local superintendent of schools or other designated official to review the educational situations of all children entering, enrolled in, or leaving special education services.

Members of these committees include a chairperson assigned by the superintendent; a special educator; interdisciplinary personnel from public agencies and the health department; as well as representatives of appropriate agencies and individuals who are familiar with the student's current level of functioning.

COMMUNITY BASED

In the local community or rural area where the child and family live.
Restrictive or institutional care should be accessed for brief stabilization only.

ESY Service

Extended school year service.
Individualized extension of *specific* services provided beyond the usual school year as part of a free, appropriate public education in accordance with the student's Individualized Education Program. This is for students who exhibit the need for special education and/or related services throughout the calendar year.

LRE

Least restrictive environment [or LRS, least restrictive setting.
Treatment program or facility in which needed services are delivered in the environment [setting] that the child is usually *served* in. In federal law, LRS is referred to as LRE.

SPECIAL EDUCATION SERVICES

Specially designed programs of instruction, provided at no cost to the parents to meet the unique needs of the disabled student.
(This does not include costs that are normally charged to non-disabled students as a part of the program--school pictures, class rings, yearbooks, etc. These services can include classroom instruction, home instruction, and instruction in institutions and hospitals.

AGENCY ABBREVIATIONS

AFB	American Federation for the Blind
ALU	Alternative Living Unit
ARD	Admission, Review and Dismissal Committee
CARD	Central Administration, Review and Dismissal Committee
CAP	Corrective Action Plan
CBLA	Community Based Living Arrangement
CBLP	Community Based Living Plan
CESS	[Division of] Compensatory Education and Support Services
COMAR	Code of Maryland Regulations [Bylaws]
CRT	Criterion Reference Test
CSPDC	Comprehensive System of Personnel Development
DBFP	[State] Department of Budget and Fiscal Planning
DSE	Division of Special Education
EEEP	Extended Early Education Program
EIPP	Early Intervention and Prevention Program
ESD	Extended School Day
ESY	Extended School Year
FFY	Federal Fiscal Year
FY	Fiscal Year
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
LEA	Local Education Agency [Public School System]
LCC	Local Coordinating Council
LRE	Least Restrictive Environment

M/E	Monitoring and Evaluation
MANSEF	Maryland Association for Nonpublic Special Education Facilities
MSB	Maryland School for the Blind
MSD	Maryland School for the Deaf
MSDE	Maryland State Department of Education
MSPAP	Maryland School Performance Assessment Program
MSPP	Maryland School Performance Program
NASBE	National Association of State Boards of Education
NFB	National Federal for the Blind
OCYF	[Governor's] Office of Children, Youth, and Families
OSEP	Office of Special Education Programs [U. S. Department of Education]
PARD	Public Agency Requirement Document
PITC	Parent Information Training Center
RICA	Regional Institute for Children and Adolescents (Baltimore, Southern Maryland, and Rockville)
RTC	Residential Treatment Center
SEA	State Education Agency [MSDE]
SCC	State Coordinating Council
SOP	State-Operated/State-Supported Program
SSIS	Special Services Information System

About the Authors

Raymond Pitts, Jr., is the father of six children, one of whom is a severely and profoundly mentally disabled son. Currently, Dr. Pitts serves as a member of the Maryland State Department of Education Subcommittee for the implementation of Senate Bill #588. His studies of critical factors in programs for the mentally handicapped led to his development of a model for successful group homes. He recently retired from 20 years of marketing management experience with the IBM Corporation.

Raymond Pitts, III, is 17 years old. On May 20, 1993, he became one of the first cases to return from out-of-state residential placement to a Montgomery County community-based program under the auspices of Systems Reform Initiative. In a few years, Raymond will no longer qualify for programs through the Board of Education. **In this guidebook, Dr. Pitts uses his own family's experiences to offer suggestions to other families who embrace systems reform and need to plan for adult wrap-around care.**

Carolyn Marchitell is the sister of a 46-year-old man with Down's syndrome. She has been teaching for more than twenty-five years in public high school and private college. In her research, consulting, and advocacy projects, she designs collaborative communication and management strategies for institutional change.

Dr. Marchitell's brother, James Michael Kuethe, now travels by bus to work for spending money. His adult group home, operated by Ohio Valley Residential Services, is supported cooperatively by Hamilton County, the State of Ohio, and federal agencies. Their 82-year-old mother, Mary Rentfrow, still coordinates the programs which provide his care. **This family's situation dramatically illustrates the life-long challenge which faces families with special children.**

The authors continue to work as researchers and advocates, developing and managing support programs to enhance cooperation among families, agencies, and institutions to meet the needs of mentally disabled individuals. They are the authors of ***Ray's of Hope***, a book about the special child and the family.

Through their special blend of personal experience and professional expertise, these authors provide valuable insights for any family whose plans must include lifetime care for a critically dependent child.

Project Return: A Parent's Guidebook **describes how to assure, coordinate, and individualize wrap-around care.**